

How HIV changes the faith
The religious experience of support group members in KwaZulu-Natal

Philippe Denis OP
University of KwaZulu-Natal

It is now widely recognised, in public health institutions and in the academia, that religion, alongside other factors, has an impact on the course of the HIV and AIDS epidemic in sub-Saharan Africa. The response of religious institutions – and of the Catholic Church in particular – to HIV and AIDS in the field of care and treatment has been massive. They have initiated, complemented or supported western-based biomedical programmes throughout the continent¹. Religious institutions were among the first to run AIDS prevention campaigns in Africa. Yet on two issues, religious leaders clashed head on with governments and health authorities in matters of AIDS prevention: the use of condoms and sex education.² Critics have pointed out that the link between sex, sin and immorality often made by Christian ministers and preachers and internalised by large sectors of the African community added to stigma attached to HIV and AIDS³. Religious institutions shape the discourse on HIV and AIDS. They add meaning to the epidemic and mediate the prevention messaging. They influence not only what is said but what is not said on HIV and AIDS.⁴

If the role of religious institutions in the evolution of the epidemic is undeniable, one should not underestimate the influence HIV and AIDS exerts on religion itself. The epidemic changes faith and religious practice in local communities. There is a relation of mutual influence between HIV and AIDS and religion.

¹ Several papers read at the Cedara conference document the role of the Catholic Church in HIV and AIDS care and treatment. On the history of Christian responses to HIV/AIDS in sub-Saharan Africa, see Philippe Denis, "HIV, AIDS and Religion in sub-Saharan Africa: An historical survey", in Beverley Haddad, ed., *Religion and HIV and AIDS: Charting the Terrain* (Pietermaritzburg: University of KwaZulu-Natal Press, 2011), pp. 57-77.

² On the debate on condoms and sex education in Africa, see John Illife, *The African Aids Epidemic. A History* (Oxford: James Currey, 2006), pp. 96-97; Stephen Joshua, "A critical historical analysis of the South African Catholic Church's HIV/AIDS response between 2000 and 2005", *African Journal of AIDS Research*, 9 (2010), pp. 437-447.

³ Catherine Campbell, Carol Ann Foulis, Sbongile Maimane and Zweni Sibiyi, "I Have an Evil Child at My House: Stigma and HIV/AIDS Management in a South African Community" *American Journal of Public Health*, 95 (2005), p. 810.

⁴ Jean-Pierre Dozon. "From the social and cultural appropriations of HIV/AIDS to necessary political appropriations: some elements towards a synthesis", in Charles Becker, Jean-Pierre Dozon, Christine Obbo and Moriba Touré, eds, *Vivre et penser le sida en Afrique - Experiencing and understanding HIV/AIDS in Africa* (Paris: Karthala, 1999), p. 692.

This mutual influence has to be seen in a historical perspective. The thirty-year-old long HIV and AIDS epidemic is an evolving phenomenon. In southern Africa, after a slow increase of the infection rate in the late 1980s and early 1990s, the number of AIDS-related deaths started to increase dramatically in the late 1990s to remain at an alarmingly high level until the South African government rolled out an ambitious and fairly effective ARV programme. The infection rate, however, remains high. In the early days of the epidemic the response of religious institutions, the Catholic Church in particular, was occasional and geographically limited. After 2000 it became more effective thanks to mobilisation at grassroots level and funding from international organisations and public health agencies. The churches could see the impact of the epidemic on the lives of their members. They felt compelled to take action. In recent years the impact of faith-based interventions has been more limited due to reduced funding. Meanwhile HIV and AIDS has become part of the landscape, for all sectors of society including the churches. This paper argues that since the outset of the epidemic new attitudes and behaviours have developed in South Africa not only with regard to sexuality, gender and public health but also spirituality, theology, morality and church life.

The main source of information for this paper is a set of oral history interviews conducted between July and December 2011 in the Pietermaritzburg area as part of the “Memories of AIDS Project”, a research programme of the Sinomlando Centre of the University of KwaZulu-Natal supported by the National Research Foundation of South Africa (NRF) and the South Africa Netherlands Research Programme on Alternatives in Development (SANPAD). For this particular paper ten interviews, with an accumulated recording time of twenty-two hours, were selected.⁵ All interviews were conducted by Ntokozo Zitha, a Zulu-speaking graduate of the University of KwaZulu-Natal. She made use of a topic guide designed by the research project steering committee. Like the other fieldworkers she was asked to engage the research participants on issues such as power, sexuality, gender, disease stigma, religion, faith and community support.

The two men and eight women who agreed to be interviewed belonged to Fountain of Life,⁶ a support group of people living with HIV established in Pietermaritzburg in 2003. All members of this informal body are HIV positive. They meet once a month, usually on a Sunday. They share stories and encourage one another to take their antiretroviral medication. Some go to clinics and hospitals to engage in HIV awareness. With the help of faith-based NGOs, the Pietermaritzburg Agency for Community Social Action (PACSA) for instance, they distribute food parcels and money for transport

⁵ During the first phase of the project (2008-2010) 41 interviews of pastoral agents and NGO workers involved in the fight against HIV and AIDS in the Umgungundlovu District, KwaZulu-Natal, were conducted. The target for the second phase of the project (2011-2013) is 60 interviews and 10 focus groups. On completion of the project all the interview transcripts and audiotapes will be accessible to researchers at the Alan Paton Centre, University of KwaZulu-Natal, Pietermaritzburg.

⁶ To respect the confidentiality of the informants, all names of persons as well as the name of the support group have been changed.

to their members. Fountain of Life is not supported by or affiliated to any particular church but the majority of its members, including Mary Khumalo, the founder, have strong Christian convictions.

All the research participants were confessed Christians but only eight were regular churchgoers. Three belonged to mainline churches (Methodist, Dutch Reformed and Seventh-Day Adventist), four to Pentecostal churches (the Oasis of Workshop Tabernacle, the Pietermaritzburg Christian Fellowship and an unspecified Pentecostal church) and the remaining four to African independent churches (St John's Apostolic Faith Mission, Christian Catholic Apostolic Holy Spirit Church in Zion and Twelve Apostles Church in Zion). Of those who worshipped in a Pentecostal church two were from a Catholic background. One moved from one Pentecostal church to another.

Previous studies showed that, when AIDS started to take its toll in southern Africa, the western-based biomedical approach, which defined AIDS as a deficiency of the immune system caused by a virus called HIV, the Christian message, which, directly or indirectly, presented HIV and AIDS as the consequence of sin, and the traditional belief systems, which explained the phenomenon of multiple deaths as the result of a lack of harmony between the living and the dead due, among other reasons, to the transgression of cultural taboos, were in open competition, creating conditions for confusion, shame, silence and denial.⁷ People living with HIV and AIDS, especially women, suffered from being blamed for bringing the disease to the community⁸.

The interviews suggest that the situation is changing. Despite their pain and anger the dominant trait of the interviewees was their assertiveness. They understood better their condition and knew how to distinguish the biomedical causes of the disease, the language of the church and their own spiritual experience. They showed a surprising ability to counter the accusations thrown at them by spouses, relatives and community members. They knew that these allegations were unfounded and were able to express it. The interviews revealed the irritation or, more accurately, the anger, that the attitude of men towards women in matters of sexuality and disease provoked in women.

One of the most interesting aspects of the Fountain of Life support group members' was their ability to articulate a religious discourse on their experience as people living with HIV. In contrast to the message often conveyed by religious institutions, especially in the early years of the epidemic, of HIV and AIDS as punishment of God or, in its milder form, as the inevitable consequence of a moral transgression, the Fountain Life members refused to take any blame, religious or not, for their HIV condition. Rather they emphasised, when speaking of their religious experience, positive aspects

⁷ Peter Delius and Clive Glaser, "Sex, disease and stigma in South Africa: historical perspectives", *African Journal of AIDS Research*, 4 (2005), pp. 20-36; D. Posel, K. Kahn & L. Walker, "Living with death in a time of AIDS: A rural South African case study", *Scandinavian Journal of Public Health*, 35 (2007), pp. 138-146.

⁸ Suzanne Leclerc-Madlala, 'Demonizing women in the era of AIDS : an analysis of the gendered construction of HIV/AIDS in KwaZulu-Natal', unpublished PhD thesis, University of Natal, 1999.

such as love, compassion, reconciliation and forgiveness. Crucially, they put more emphasis on the fact of being still alive – thanks to the ARV treatment the power of which was attributed to God – than on being under the threat of death. Many interviewees were able to articulate spiritually and, one may say, theologically, their views on God, Jesus, the church and Christian morality in a context profoundly transformed by the widespread availability of ARV treatment.

In response to a question on the effect of HIV on her relationship with God Mary, the founder, described with a great richness of expression the journey which took her from anger to peace of mind. At first she rebelled against God who had permitted her to be infected despite the fact that she “behaved herself” and avoided “sleeping around.”

My relationship with God has gone through a lot of changes. As I said, there was a time where I was a very angry with God. I felt angry at a number of levels. Why me?

I behaved myself. I was not sleeping around. Why did he allow this to happen to me? You know that kind of thing. And then I became reckless and don't care. Nothing good happens, you know.

So I went into relationship with my husband. We got the child, got married later on. He died through that short marriage. It was hell.

My anger definitely goes to the Creator. If you tell me: “I knew you and I chose you to be mine and I have created you. I have no plans to harm you.” Then I get harmed. Even if it is not you, why let the devil harm me?

So it was a journey of finding me and finding God and re-defining who God is to me from the stubborn woman, rebellious young woman to learning to humble myself to his feet.

And I appreciate who he is and I am surrendering to his will. Once I did that, a lot of things started to flow. But he lets me re-sit, he lets me fight, he lets me throw tantrums. We had that relationship. I throw tantrums. I ask questions. I believe if we don't listen to a person, who cannot answer you.

So what is the point if there is no relationship? Why should I believe his word? But I am learning because I have been on depression treatment three times.

It was, she summarised, “a journey of finding me and finding God and re-defining who God is to me from the stubborn woman, rebellious young woman, to learning to humble myself at his feet.”

When asked how she managed to live positively with HIV and AIDS, Bridget brought into the picture the traditional Christian teaching that life and death are in God's hands, but instead of seeing it as an invitation to passively accept HIV and AIDS as the will of God, she interpreted it as saying that people living with HIV were no more at risk of dying young than anybody else. God had the power to let them live as long anybody:

Because when I look at it, it does not mean that if I am HIV positive tomorrow I will die. Somebody can walk on the road at this very moment and get smashed and die. Nobody knows who will go away. Only God knows that Bridget is going to close her eyes today. No doctor, nobody will tell me, "You are going to die tomorrow." I said, no. My God knows it, "This is your day."

Nontokozi, who had led a turbulent youth, described her journey of recovery as a return to God:

I prayed to God when I was sick, when I lost my husband. God knows where I come from. He knows I come from a rubbish bin that has got worms. I said, "Please give me a second chance so that I can be a living testimony. What I already do in my life, I want to transmit it to other people's lives."

The ARVs feature prominently in this oral narrative. To Nontokozi they are the expression of God's benevolence:

I took Christ as my personal Saviour. I took him as my Saviour in these ARV tablets, before I put them in my mouth. When I come from the clinic, I say, "Lord, this is nothing you can do better than these tablets."

Thandeka, who combined Christian faith and belief in the power of the ancestors, made the point that God should not be blamed for her HIV condition because, thanks to the pills, she was still alive:

I do not blame the ancestors because they are not God. Even God I do not blame him. Why did I have the disease? Why did he not protect me because I praise him? I cannot blame him. I do not blame anyone because I do not even know how I got HIV. I do not blame anybody because God has protected me until now when I am taking my pills. I do not blame the ancestors because they are not God. They do not see that I am taking the treatment. It is only God who knows that I take the treatment because I pray.

The most articulate of all the interviewees on religious matters was Nontokozi. She made a long speech to explain that the ministers of religion who refused to promote condoms in church were wrong because many born again Christians were infected. They did not trust the power of the Holy Spirit:

They say a child of God does not use condoms and then I say, "Please, can you show me in the Bible where it is written about condoms?" I use to say at this point that we put the Holy Spirit aside because

we all have the Holy Spirit, the one of speaking in tongues, because we speak about the reality of life.
[...] I feel sorry for my church because a lot of people have died of AIDS in my church.

Likewise she was adamant that the ARV treatment was wanted by God. If she had the power, she insisted, she would go to Parliament and ask the government to close the churches who speak against the treatment.

They say that if you are a child of God, you do not take the treatment and I will say: Can you please page for me in the Bible and show me where that is written. Jehovah is not against the treatment because if he was, we would not have the doctors, the scientists and all those who have a hand in discovering the treatment, and those who diagnose people who have diseases.

The reluctance of church people to face the reality of HIV and AIDS is another common theme in the interviews. Beatrice, the new coordinator of Fountain of Life, spoke about this at some length. Her pastor had allowed her to speak to the congregation, she explained, but the sentiment continued to prevail among the worshippers that people living with HIV were people who “sleep around”:

We have been trying to engage with churches because... in the churches... They don't want to talk about HIV and AIDS. I am so thankful because my pastor is somebody with whom I have been able to sit down... I told him about my experience and he is very open about it since. Like now, we are trying to open a desk in the church. It is because a lot of people in the church are dying. It is because they cannot talk. It is because when they find that somebody is HIV positive they say he has been sleeping around. It is not that this person has been sleeping around to be infected. There are many ways for a person to be affected by the virus.

The problem, according to her, was the people in the church “always judge”, especially if they are “born again”:

We always judge ourselves. This one is a born again. What happened? You see. This is what we try to break in the churches. And it is not only my church. I want to go to the other churches as well.

George, a white man who works in the media sector, had the same experience. In his church nobody said anything about HIV and AIDS because they were not able to face the reality of the disease:

Some people in the church when they get to hear that somebody is HIV positive, it is really as if he is about to die, you know. Maybe by sitting next to them they are going to get it, you know. They do not really understand that the church is more kinda like... You understand what I'm saying.

Conclusion

Despite the wider availability of antiretroviral drugs the battle against the HIV and AIDS epidemic is far from being won. Any reflection on the ministry of the Christian churches in this area should take into account the fact that, in South Africa as in other parts of Africa, the epidemic has moved to a new phase. Even though infection levels remain high, fewer people die. Now that the fear of an inevitable death has been removed, at least to some degree, HIV positive people start to look more positively at their experience. Their Christian faith helps them to see that their continuing good health is a gift of God. Some of them have beautiful words to describe the spiritual journey they have pursued since they discovered that they were HIV positive.

Stigma recedes but is still very strong. The stereotype of the "loose woman" who causes men to be infected because of her bad behaviour remains prevalent. HIV and AIDS is and remains a gendered phenomenon. Fewer men than women disclose their HIV status and go to the clinic for treatment. HIV positive people still face stigma, gender oppression and various forms of discrimination.

This study suggests that new developments are taking place in South Africa. The Fountain of Life members interviewed for the project refused to be blamed for their condition. Some took responsibility for past failures but they did not believe they were infected because of their sins. They did not hesitate to criticise their church leaders when they feel that they contribute, passively or actively, to HIV and AIDS stigma. They expressed the desire to talk about their condition and to promote ARVs. Many wanted their churches to encourage the use of condoms because, in the current of state of gender relations in South Africa, even among church members, it was the only way to prevent the spread of HIV/AIDS.